Witness Name: GRO-B
Statement No.: WITN3283001
Exhibits: Nil
Dated: 5/7/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 20 June 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1954 and my address is known to the Inquiry. I am legally separated and live by myself. I am in full time employment in a technology role for GRO-B.

2. I was infected with Hepatitis B from a contaminated blood transfusion in 1985. I will discuss the impact that this has had on my health, both physical and mental.

Section 2. How Infected

Transfusion

3. When I was about 25, I had been having some gynaecological problems. I was admitted to hospital one day with horrendous abdominal pain, which was found to be a strangulated fallopian tube. I had this and one of my ovaries removed.

4. My remaining fallopian tube was badly damaged, and I was told that it was highly unlikely that I'd ever be able to have children. They were pioneering IVF at the time, but that was a long way off.

5. My husband and I decided to adopt. At the beginning of 1984, we adopted our baby girl, GRO-B

6. By Christmas of the same year, I found out that I was pregnant with GRO-B I had been so unwell with what ended up being morning sickness, but of course pregnancy was the last thing it was put down to.

7. At approximately 27 weeks, I was admitted to the Queen Mother Hospital, Glasgow, with a grade 4 placenta praevia (major), where the placenta completely covers the cervix. This is the most serious type of placenta praevia.

8. I was in hospital for 4-5 weeks, because they knew that I could have haemorrhaged at some point.

9. I did have a major haemorrhage, on 18 June 1985. I remember having a chat with one of the staff nurses and thinking that I didn't feel very well. I just remember feeling as if I was burning. I looked down and there was blood everywhere. I was rushed into theatre for an emergency caesarean. Even just in the time of getting rushed up to theatre, I lost four units of blood.

10. During my stay in hospital, I was advised that I had had a blood transfusion of approximately three units. A doctor told me that this was why I hadn't been able to go home for weekends – they'd been worried this would happen.

11. Absolutely no discussions took place around any risks of infection.

12. I was really quite ill afterwards, but I had nothing to put a comparison on because I hadn't given birth before. It was a particularly traumatic birth, so I put it down to that. I don't know if it had anything to do with the Hepatitis B kicking in or not.

Diagnosis

13. Nine years after I gave birth, I went to donate blood with the Glasgow Blood Transfusion Service, with a view to becoming a regular donor. I gave them a pint of blood.

14. Within a couple of weeks, I got a letter on a Friday at tea time. We were going on holiday on the Saturday. It basically said, "Thank you for donating blood, however we are sorry to advise that we aren't able to use it because a liver infection has been detected, but please be advised it's not HIV/AIDS." It gave a number to call.

15. I was frantic with worry. I phoned the number. It was just a quick phone call to say that it was Hepatitis B and to just go on holiday, to refrain from alcohol, not to share razors, glasses or straws and they'd see me when I came back.

16. Throughout the holiday, I was worried. My enjoyment was curtailed due to the paranoia of being infectious.

17. When I got back, there was another letter with an appointment to see Dr Watkins and Dr Frame. They were in the Glasgow Blood Transfusion Service. They quizzed me about whether I drank or did drugs, or whether

my husband or I had engaged in promiscuous sex. I have not. I had my ears pierced when I was about 20, at a really reputable place.

18. This caused extra stress on my marriage, because our relationship was not good at this point.

19. He used to get so annoyed. We had such friction – my paranoia was just awful. He was saying, how do you even know it was a blood infection... Implying adultery on my part.

20. During recent conversations with relatives, there was a recollection that myself and my siblings all had replacement transfusions as newborn babies. I was also quite shocked to learn that my mother had miscarried her first 2 pregnancies at quite a late stage. I learned that was because of my mother having a rare blood type, Rhesus Negative. When my elder brother and his twin sister were born, they were 9 days old before it was discovered my mother was in fact Rhesus Negative blood type. By the time both babies were transfused, they were both brain damaged and sadly the baby girl died sometime after.

21. My older brother and my younger sister have since requested their medical records. Their evidence clearly shows both had replacement transfusions as babies.

As my medical records show I am also 'O' Positive blood type (same as my siblings), I have now requested further medical records for myself from date of my birth, for which I am awaiting a reply

Information provided

22. They were actually quite vague about it at that point, and just said that I should just moderate my alcohol intake and that it was a Hepatitis virus. I felt really let down for any information at that point. I had no idea of how it affected my liver or other health implications of it.

23. I was advised that "It was unfortunate I had the HBV, but I should be grateful that the transfusion after the birth saved my life." I should just move forward, not worry, and live my life as normal!

24. Other than not sharing toothbrushes and things, no information was provided. I don't remember anything being said about risk of transmission via intercourse with my husband.

25. They said that I would get another blood test in six months. I insisted that I wanted all my family tested. They were all clear. GRO-B was about 10, but I didn't explain to her why she was being tested.

26. I had to go online to source my information, which was frightening. I read that if the infection was more than six months on and hadn't cleared, you were a chronic sufferer. I had had the virus for several years by this stage. This was how I learned that my Hepatitis B was chronic.

27. At that point they said they'd refer me on to the Brownlee Infectious Diseases Centre, (Gartnavel Hospital, Glasgow). The guy, he was very nice, and he explained how when you get Hepatitis B the cells can replicate. Mine had been replicating.

28. He said hopefully as you attend and get more blood tests that the viral cells will stop replicating. He said they were replicating only in the thousands, not millions, which was a good sign the infection was coming down. He said therefore I'd probably be lucky and not suffer severe liver damage.

29. He said to me that instead of going up to the clinic they'd get my GP to test me every six months.

<u>Should information have been provided earlier?</u>

30. When I was diagnosed, I was quite naive to the whole situation. It wasn't made out to be a very big deal. At that point, I had no reason to expect any other outcome than what had been conveyed.

31. As time went on, I was starting to get a bit annoyed and thinking, *Surely I should have had some medical attention or something.* I was kind of hoping that there was some kind of antidote or drug that could take it away. However, it was just, they'd check my blood and that was it.

32. The phone call and the letter at the beginning - I was very, very upset. To write to someone who will receive a letter on a Friday night, that was

very upsetting. The contact should have been more personal, to break news like that, absolutely.

33. I kind of felt as though they played it down. When I read it up on the internet, I felt that it was a lot more serious than they were telling me. I feel big time that I would have benefitted from that.

34. I just remember seeing something that said that it could replicate again in later life and that it could cause cirrhosis of the liver and in some cases, cancer. Because there was no support, and if you went to ask your doctor… Nobody really knew much about it. All I kept getting told was that, "You're lucky to be alive". That was the attitude and I kind of took that as gospel.

35. The doctor at Brownlee deemed that my viral load was low, but who's to say that I wouldn't have benefitted from that knowledge some time before that?

36. It would be nice to know if it was completely better. You either rid yourself of it right away or you're a chronic sufferer.

37. I was horrified to read that blood transfusions were given with blood donated from high risk sources. It is also very alarming to read that some medical records have gone missing, and the possibility of government documents being destroyed.

38. I am shocked to hear that a Health Secretary has actually been able to provide evidence that some patients' medical records were changed in order to make it look like their health issues were self-inflicted.

39. I am now angry that patients could have been advised earlier, and diagnosed earlier. This did not happen because of a possible cover up.

Section 3. Other Infections

40. I am not aware of any other infections I received as a result of the infected blood.

Section 4. Consent

41. I am not aware of any tests being done without my knowledge or permission.

42. I gave my consent for a lot of blood tests to be taken when I started experiencing early onset menopause aged 37.

43. I have also given consent for general blood tests during routine doctors' visits if I was feeling poorly. I don't know if they were used for any other reason.

Section 5. Impact

Mental

44. I was actually very naïve and scared at the time about my future health. I was reading up on documents which suggested that the longer you left the virus, the higher the risk was to your liver developing scarring and even causing cancer.

45. I remember thinking, *Oh my god, they've missed all this, and I've lost all this time to do anything about it. What happens if I take ill?*

46. As a Hep B carrier, I was constantly worried about being contagious. I was paranoid about sharing items and having cuts, thinking that I had to get a plaster on right away.

47. I wouldn't hold peoples' babies because I was worried they'd find out I'd had Hep B. I'm not saying that I wouldn't have felt like that either.

48. I had no guarantee that saliva or just kissing somebody, that I wasn't infectious. Even like a glass of alcohol, if somebody wanted to taste my drink – you were over-defensive about things.

49. I had stages where I couldn't make plans because I didn't know how I was going to feel on the day. I put it down to hormones and I couldn't tell if I'd had brain fog.

50. My husband and I weren't getting on at all. He was getting sick of how paranoid I was about passing on infections. My paranoia made him so annoyed. We had some big arguments, there was a lot of friction.

51. I wanted my husband to use contraceptive. We hadn't needed to previously, because we thought I was infertile. He didn't want to, and that caused even more grief for our relationship.

52. One year we had an argument in a car park because I couldn't remember where we parked. I had walked away. My daughter said "If you and dad leave each other then I'll run away and you'll never see me again." I had a couple of friends who used to say to me, "Why are you still in this relationship as you seem really unhappy?"

53. I was paranoid about germs and keeping clean. We all had our own cups in the house. I used to shout at the kids if they touched my toothbrush, or if they were lifting my fork. It sounds silly, but I didn't know anything different.

54. I constantly scolded them for using any of my items, and was paranoid about them having open wounds.

55. I would shout and get angry at the kids thinking, I can't explain this to them.

56. I also gave up on all alcohol for fear of damaging my liver further.

57. Even to this day it's affected me because I have had a couple of nice partners but I've not really developed any full relationship. Once, when I thought it was going to develop into a serious relationship, I told him that I was a Hep B carrier. He said it didn't bother him, but a week later it was all over and he left me. It is difficult to tell somebody.

58. I experienced depression at one point, just a few years ago. I had a lot of back pain. Really badly. I went to a pain management clinic. The consultant there diagnosed me with depression. He suggested duloxetine, but he sold it on the basis that it was also good for back pain. I am still taking it but in a very small dose. I used to take about 5-6 times as much.

Physical

59. Physically, I felt very unwell after the birth and resulting blood transfusion. I constantly felt weak and short of breath. As mentioned though, I didn't necessarily know that anything was wrong, because I hadn't given birth before.

60. When I first came out of hospital, I was so fatigued that my GP recommended I keep my child minder on for another month. He arranged for this to be funded because of my grade 4 placenta praevia. GRO-B was in hospital for three weeks or more because he was so premature, so it was just GRO-B who I would have had to look after at that stage.

61. As time went on, it was difficult to tell if I was just tired, or if I was actually unwell. I was contending with two young children, and the fatigue was sometimes put down to that. My GP suggested that perhaps grandparents could look after children on an overnight, to provide some respite for me.

62. I was still going to the doctor on a regular basis throughout a six-year period, as I was feeling unwell all the time.

63. Then my early menopause arrived, and the fatigue would be pinned on that instead.

64. About five years ago, I was told that I have fibromyalgia by an out-of-hours doctor, but I had never been told this before. She just read it in my records. I wonder if they have diagnosed me with this, based on my constant fatigue? I've never been given this diagnosis before.

Treatments

65. I've never been offered or aware of any treatments at all.

66. I was never offered Ribavirin or other antiviral treatments. I was just told to cut down on alcohol.

67. When I was going to the Brownlee, the virus wasn't replicating in a huge way. He thought that I might be able to rid the virus, but it never actually stopped or went away, and I was told that I'd never be able to be an organ or a blood donor.

68. I'm sure that my Brownlee visits only went for a couple of years. Then they told me that I would always have a degree of the virus because I was a chronic carrier.

69. They said they would speak to my GP and ask him to regularly check my liver. I assume that they would have advised my GP of this.

70. I know it sounds really naïve but I honestly just thought, there's not a lot I can do, and I just thought that my GP was managing it.

71. I have never, ever, since the Brownlee, been told of what state my liver is in. Even though they have done full blood count tests, I have never been given an update on my condition.

Further medical complications

72. There were no further medical complications as such, because my symptoms were just confused with the menopause.

Impact upon treatment for other conditions

73. My infected status has not impacted upon my dental treatment. My dentist is very, very nice. I've been with the practice for years and years.

74. I did have a horrible experience with a vascular surgeon at the Glasgow Western Infirmary though. I developed a varicose vein across my knee in the early 2000's and was referred to hospital within a week. I had been the day before for my pre-op and declared everything about my HBV status. It was splashed all over my records. I went through it all with the doctors and nurses.

75. When I went down to the anaesthetic room, the vascular surgeon came down and shouted at me about how irresponsible I was, that I was in a vascular unit with Hep B and I hadn't let anyone know. He said I should have brought it to their attention when we went down there. This is despite it being all through my notes.

76. I have never been so traumatised in my life. There were all of these people staring at me. I went into theatre crying.

77. My brother in law went absolutely mad, he was horrified. He helped me devise a huge letter of complaint. I did receive a response. I didn't get an apology from the surgeon, but I got a bit of an apology from another surgeon.

78. The same thing happened at the Vale of Leven Hospital in Alexandria, Dumbarton. I had a biopsy taken from my womb due to an unexplained haemorrhage. My HBV status was all over my records, and I had mentioned it in the pre-op.

79. After surgery, a nurse came up to change a dressing. She raised her voice abruptly and told me that I should have told her to wear her latex gloves, "I've got young children to think about". I knew the person in the bed next to me. I felt like if I hadn't been wired up in a bed, I would have got up and thumped her one! I felt so enraged. It was so, so rude.

Stigma

80. Due to the stigma associated with Hepatitis, I've never really discussed that I am an HBV carrier. I just feel that people do have preconceived ideas with how you are infected with casual day to day contact.

81. I have refrained from any serious relationships because of my Hepatitis B. I am traumatised from the one time that I did tell a partner about it.

82. I told my two best friends and there are a couple of other people who know, because I'm not ashamed of it now. But I used to think, nobody is going to want to come into my house for dinner or pass their baby to me.

83. I'm sure there must have been lots of folk who felt like me.

Private/family/social life

84. My social life was fine. My husband and I were always on holiday and went abroad every year. In later years though, we rarely socialised together. The strain of my infected status and my fatigue became too much.

85. We could have ended the marriage earlier, but because of the kids we didn't. I think they were about 15 when we separated. That was quite traumatic because we had put money down on a plot to buy a brand new house. That was the turning point for us.

86. The worry I carried due to my status had such a marked effect on the marriage. In my mind, I just felt that he wasn't sympathetic or supportive of me.

87. When we separated, GRO-B did say she was glad. Even though they're close to their dad, the children thought it was best that we weren't together. They definitely sensed the hostility between us.

88. I have been reflecting with my son recently, in the process of giving this statement to the Inquiry. He didn't realise the impact that my infected status has had on my life in terms of not moving forward with new relationships since my marriage. He was really upset when he realised that my Hepatitis B has affected me in this way.

89. GRO-B worries about the pressure on my liver caused by the combination of having Hepatitis B, and the pain medication I take for my back. She also worries that it's been a contributing factor to a lot of the illnesses I've had over the years. She is constantly researching foods for me to eat to keep my liver healthy, and is on at me to be more proactive with doctors.

90. Neither of my children recall a specific conversation where I told them I had the virus, although GRO-B recalls me having my own cup of tea that they weren't allowed to use. She trusted that I knew what to do to keep them safe, but remembers how worried I was about things.

91. When GRO-B started her nursing training, she was tested (and vaccinated) for Hepatitis B. Part of her worried that her test would come back positive and that she wouldn't be able to do her training. She also became more aware of the risks to my health on a medical level, and this added to her worry.

Education/work/financial effects

92. I did not suffer any educational or employment effects as a result of my diagnosis with Hepatitis B, because I never told anyone. I have had to change my job, but that was due to my chronic back pain. I've always been a very "get up and get on with it" kind of person.

93. In having to declare that I'm a Hep B carrier, I constantly face increased costs. My health insurance for example, jumped up when I declared that I had Hepatitis B. My monthly payments went from something like £34 per month to something like £134 per month.

94. I was urged to take out critical life insurance, but had to cancel it because these payments were too high. I have taken out a very basic life insurance policy.

95. I had to pay an equity of our former house to my former husband which left me with a surplus if you like. The remainder of my mortgage on this property should be paid by next December – which is a few months beyond my state pension age.

Section 6. Treatment/Care/Support

96. I was never at any point offered any counselling or psychological support. It would have been absolutely beneficial for me to have had a person who could have offered guidance and assurance.

97. You're basically just getting told you've got something and you're reading all these horrible things on Google. If I had been offered something like that, I wouldn't have been so paranoid about it.

98. This was at the time when HIV and AIDS were rife in the media. There was always this perception that if you had infected blood that it led to HIV/AIDS.

Section 7. Financial Assistance

99. I wasn't aware of, nor offered any financial support as a result of being infected with Hepatitis B.

Section 8. Other Issues

100. I am not legally represented in this matter, nor have I been involved in any campaigning.

101. There has been no proper monitoring from my GP in relation to my condition. I'd be very interested to see my medical records, to ascertain if instruction was received from the Brownlee Clinic and what my GP practice was advised. They should have followed this up better. It's been very dismissive. It was just, "You should be okay, so we're just going to discharge you from here."

102. The fact that to this day I still don't know what the status of my condition is, is actually quite profound.

103. Going through this statement has been a bit of an emotional journey and has made me realise how much this has actually impacted me.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-B

Dated 5/7/2019